Outcomes:

Work Group 1:1 Interviews

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Objectives

1. Review project methodology; participants
2. Present findings
   A. Themes
   B. Gaps
3. Introduce possible collaborative strategies for future consideration
4. Discuss possibility of drafting shared definition of peer support
Methodology

• Standard interview questionnaire developed in March 2018
• Interviews with each Work Group member/ team conducted March – April 2018
  – Consistent interviewer
  – Consistent scribe
  – Calls recorded
• Executive Summary developed
  – Themes identified
  – Gaps identified
Who are we?
Getting to know Work Group members a bit more...

- TS Alliance and BDSRA founded >30 years; most less than 10 years old
- All were founded by families; except CNF
- Define themselves:
  - 9/12: Disease/condition specific
  - 3/12: Broader child neurology “eco-system”
- All utilize volunteers in some capacity
- 8/11 engage multi-stakeholders for organizational capacity (Scientific, Medical, Corporate and/or Governance BOD)
- 9/12 report providing peer support currently
- 3/12 do not report providing peer support; but do provide social media platforms for “connections”
Overall Themes

**Breadth of Task**
- Geography
- Ages
- Stages of disease/ range of diseases
- Small staff

**The Human Aspect**
- Managing conflicts
- Choosing competent peer support “providers”
- Managing the “passion”

**The Role of Information**
- Educating caregivers
- Countering false information
- Preserving patient expertise & experience
Theme: Accessing peer support

- Great variance in responses to questions aimed at assessing face-to-face intervention vs. virtual

- Face to face meetings (International, Regional, Local)

- Social Media’s role in peer support
  - 11/12 of Work Group members provide social media platform for caregivers to connect (all but CNF)

- Referral sources:
  - 2/12 access via clinic sites
  - 6/12 receive referrals per physicians
  - 2/12 receive referrals from social workers
  - 1/12 receive referrals from genetic counselors

- 100% report access via phone and email
Theme: Training

- 9/12 organizations report providing training
- Majority of training focused on content to be provided (i.e. dx)
- 4/12 provided expectations on peer support; training manual; organizational information
- Definition of “regular training” varied
Theme: Peer Support Infrastructure & Funding

• Peer support was ‘housed’ within:
  – Patient engagement
  – Patient advocacy
  – Outreach programs & services
  – Child & family support programs

• Majority of costs related to peer support funding were incurred in organization’s general operating expenses

• Some received corporate and/or individual donations
Interview Findings

Gaps
Gap: Lack of shared definition

Examples provided:

- “A caregiver looking for another caregiver to lean on for support.”
- “Support provided 1-on-1 by one individual to another.”
- “Desire to connect with someone that understands what they are going through.”
- “Support given by those who get it, who understand my child.”

Implications:

- Lack of clarity may lead to lack of legitimacy
- Lack of clarity may lead to cumbersome program development & funding
Gaps: Legitimacy of peer support as a caregiver support intervention

- 100% consensus of the importance of peer support within advocacy groups vs. variance in report about evidence-basis

- 100% consensus on the need to increase child neurology community’s awareness on peer support

- Barriers to awareness: lack of technical assistance in peer support provision; lack of portal to share lessons/needs; lack of training and ongoing mentorship; physician engagement

**Implications**

- Lack of awareness may perpetuate sense of “one friend talking to another”

- Lack of awareness may inhibit more families being served

- Lack of awareness may perpetuate our own false narratives
Gap: Physician engagement

“Would be a game changer”

“Shorten the time families feel isolated”

“Assist in families not feeling like they are the only ones”

“Make it ok (legitimatize) the need for support”
Gaps: Need for Technical Assistance (program development & training)

- Screening for those who provide peer support
- Identifying program outcomes; measuring outcomes
- Consistent training for peer support “specialists”
- Provision of ongoing mentorship of peer support “specialists”

**Implications:**

- With reality of small staff/resources vs. great need and content, is a collaborative strategy to reframe peer support from organization based to community based possible?
Where do we go from here?

Setting collaborative priorities and next steps
Collaborative Opportunities Identified

1. Need to establish a clear, shared definition of peer support

2. Coordinate resources & expertise to augment organization-focus peer support to community-based peer support services

3. Create greater awareness of the evidence-based practice, and legitimacy of peer support (i.e. engage with referral sources)

4. Provide technical assistance in peer support program design/ management, training, and on-going mentorship
No universally accepted definition.

"Peer support is a system of giving and receiving help founded on key principles of respect, shared responsibility, and mutual agreement of what is helpful. Peer support is not based on psychiatric models and diagnostic criteria. It is about understanding another’s situation empathically through the shared experience of emotional and psychological pain. When people find affiliation with others they feel are 'like' them, they feel a connection. This connection, or affiliation, is a deep, holistic understanding based on mutual experience where people are able to 'be' with each other without the constraints of traditional (expert/patient) relationships."

(Mead, 2001)
Shared definition of peer support

• Throughout interviews, common language utilized in our community:
  – “One” to “Another”
  – “1-on-1”
  – “Support”
  – “Understands” “Gets it” “Lean on”
Proposed shared definition of peer support (FOR REACTION)

• Peer support is a process in which reciprocal support is facilitated by one trained individual who shares his/her common life experience with another individual. This supportive, fluid process aims to enable mutual empowerment and a sense of connection.

• What it is: Peer support is a process in which reciprocal support is facilitated by one trained individual who shares his/her common life experience with another individual.

• What it does: This supportive, fluid process aims to enable mutual empowerment and a sense of connection.
Unity is strength. When there is teamwork and collaboration....wonderful things can be achieved.

Mattie Stepanek
SAVE THE DATE: PEER SUPPORT BOOTCAMP – October 2\textsuperscript{nd}!

Topics to include!

• Discussing research that underscores the value, impact, and health benefits of peer support to families

• Learning best practices, key elements, and effective techniques to providing peer support that is both helpful and healthy

• Meeting and sharing experiences with colleagues who are providing peer support

• Exploring a common vision and commitment to work together, as providers of peer support, to ensure that families and caregivers have access to someone who will listen and walk with them on their journey

• Building a network of peer supporters, with the goal of enriching and diversifying assistance opportunities for the families we serve